

The linking of amyotrophic lateral sclerosis disease-specific quality of life instruments to ICF with refined rules

The linking of ALS specific instruments to ICF

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Abstract

Aim: Quality of life (QoL) has emerged as a significant concept in the domains of healthcare and medicine. Amyotrophic Lateral Sclerosis (ALS) reduces the QoL of individuals by affecting various systems. The aim of this study is to link ALS-specific QoL assessments to ICF components.

Material and Methods: The ALS assessment questionnaire (ALSAQ-40) and short form (ALSAQ-5), and the ALS-specific quality of life revised (ALSQoL-R) and short form (ALSQoL-SF) were linked to ICF using refined rules by two independent researchers.

Results: Statistical analysis results showed that the kappa value of 81.3% demonstrated almost perfect agreement between the researchers. A total of 115 concepts were defined in the study. Of the linked concepts, 54 were body functions, 54 were activity and participation, and 4 were environmental factors. All the instruments had items linked with items b152 "Emotional functions" and d330 "speaking" components.

Discussion: The majority of the items of the ALSAQ-5, ALSAQ-40, ALSSQoL-SF, and ALSSQoL-R were linked to the activity and participation categories of ICF. The ALSQoL-R, ALSQoL-SF, and ALSAQ-40 were linked mostly to body functions. It was seen that ALSQoL-R had the most unique linked concepts in body functions, and ALSAQ-40 had the most comprehensive linked concepts in the context of activity and participation. It can be recommended that ALS-specific QoL instruments to be developed in the future include domains of ICF, products and technology, natural environment and human-made changes to the environment, services, systems and policies, recreation, and leisure.

Keywords

ICF Linking, Quality of Life, Outcome Measure, Amyotrophic Lateral Sclerosis, Activity And Participation

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Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease of the central nervous system that results in the loss of upper and lower motor neurons in the cortex, brain stem and spinal cord [1, 2]. According to recent studies, the incidence of ALS is between 0.6 and 3.8 per 100000 people, and prevalence is between 4.1 and 8.4 per 100.000 people. ALS is known to be 1-2-fold more common in males than females, and the age of disease onset has been reported to be 51-66 years [1]. ALS is categorized as sporadic or familial. The sporadic type accounts for approximately 90-95% of all cases, and the familial type for 5-10% of all cases due to their associated genetic inheritance factors [3, 4]. Muscle weakness, twitches, and cramps are the most common symptoms in both types of ALS [5, 6]. ALS reduces the QoL of individuals by affecting various systems [7].

Quality of life (QoL) has emerged as a significant concept in the domains of healthcare and medicine, and is now emphasised in both study and practice. The World Health Organization (WHO), the current definition of QoL is “An individual’s perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns” [8]. Understanding QoL is vital to be able to improve the symptom treatment, care, and rehabilitation of patients with ALS. QoL constructed within the strict boundaries of dependency has become even more crucial because of the progressive nature of ALS with a decline in life expectancy. Therefore, precise and disease-specific evaluation of QoL in patients with ALS is essential.

The International Classification of Functionality, Disability, and Health (ICF) is a comprehensive system designed to create a common language across different disciplines and fields to be able to improve the quality of service. The main categories of the ICF framework are functioning, disability, and contextual factors. Functioning and disability consist of body structures (s), body functions (b), and activity and participation (d). Contextual factors include environmental (e) and individual (pf) factors. The ICF presents a hierarchical taxonomy containing more than 1400 categories [9].

Earlier studies have linked the ICF to a diverse range of diseases [10-13]. The linking of disease-specific instruments to the ICF is thought to guide the appropriate selection of scales to assess the areas in which patients experience functional loss. To the best of our knowledge, there is no research linking ALS-specific QoL assessments with the ICF. Therefore, the aim of this study was to link QoL assessments specific to ALS with ICF components. In line with this, the research question of our study is as follows:

- To what extent are ALS-specific quality of life scales linked to the ICF?
- Which subcategories of the ICF can ALS-specific quality of life scales be linked with?

Material and Methods

The scales developed specifically for ALS and for evaluating QoL were determined with reference to the literature, and the scales used in this study were as follows:

The Amyotrophic Lateral Sclerosis Assessment Questionnaire

(ALSAQ-40) was developed by Jenkinson et al. as a self-reported outcome measure to evaluate QoL specific to patients with ALS and motor neuron disease. The ALSAQ-40 includes 40 items in the five sub-parameters of physical mobility, activities of daily living/independence, eating and drinking, communication and emotional functioning [14]. The patient responses refer to the last two weeks. Each item is scored between 0 and 4 points with the total score obtained by dividing by the maximum score that can be obtained from the scale. The final ALSAQ-40 score ranges from 0 to 100, with lower scores indicating better QoL, and higher scores indicating lower functional levels[14].

The Amyotrophic Lateral Sclerosis Assessment Questionnaire Short Version (ALSAQ-5) is a revised version of the ALSAQ-40. The ALSAQ-5 consists of 5 items, each scored between 0 and 4 points by the patients, to give a total score then divided by the maximum score. The final score of the ALSAQ-5 varies between 0 and 100, with lower scores indicating better health, and higher scores indicating lower functional levels. In a previous study, the ALSAQ-5 showed a strong correlation with the ALSAQ-40 [15]. The Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised (ALSSQOL-R) is a self-report outcome measure that evaluates QoL in patients with ALS. The ALSSQOL-R consists of 50 items in six sub-domains of negative emotion, interaction with people and the environment, intimacy, religiosity, physical symptoms, and bulbar function. Scoring is applied to 46 items, each scored between 0 and 10 points. The total score of the ALSSQOL-R ranges from 0 to 460, and the average score is calculated as the total of all the items divided by 46. A higher average score indicates better functional levels for QoL[16].

The Amyotrophic Lateral Sclerosis Specific Quality of Life- Short Form (ALSSQOL-SF) is a revised version of the ALSSQOL-R. The 50-item scale was revised to the short form of 20 items in 2018 [17]. Each of the 20 items is scored between 0 and 10 points, to give a total score range of 0 to 200. The average score is calculated as the total of all the items divided by 20. A higher average score indicates better functionality for QoL [17].

The ICF Linking Process

The ICF linking was made within the framework of the refined association rules set by Cieza et al. in 2016 [18]. The linking process was performed in three stages. In the first stage, the researchers investigated each item of all scales in order to identify main and secondary concepts. In the second stage, two researchers (MD, EAR) examined the perspectives and responses of each item. The perspectives were categorized as “Appraisal, Need or Dependency, Descriptive; Capacity and Descriptive; Performance”, and responses were categorised as “Intensity, Frequency, Agreement, Confirmation and Qualitative Attributes”. In the second stage, the main and secondary concepts of the relevant items were independently linked using an online website (<https://apps.who.int/classifications/icfbrowser/>). Concepts that could not be linked were classified as not definable; general health (ND-GH), not definable; physical health (ND-PH), not definable; mental health (ND-MH), not covered by the ICF (NC). In the third stage, three researchers (MD, EAR, and EA) came together and reviewed all the independently conducted stages. Disagreements were discussed. In cases of disagreement, we utilized a majority rule approach and a consensus was reached on linking. Additionally,

if consensus was not reached, we consulted an external expert (EA) in ICF coding to provide an objective perspective and final decision on the appropriate codes. The language of all the materials used in the research was English.

Statistical Analysis

The study was conducted between December 2022 and February 2023. Using SPSS vn. 26.0 software (IBM Corp., Armonk, NY, USA), the Kappa score was calculated to determine agreement between the evaluators. A Kappa score in the range of 0-1 and above 0.61 indicates good agreement [19]. Frequency analysis was used to examine the distribution of scales for the ICF parameters.

Ethical Approval

Ethical and scientific rules were followed in all stages of the study; no changes were made to the data included in the study. Data open to access on the internet were used in the study. Therefore, ethics committee approval is not required. All procedures performed within the scope of the research are in compliance with the “Declaration of Helsinki”.

Results

The results of the statistical analysis showed a kappa score of 81.3%, demonstrating almost perfect agreement between the researchers ($p < 0.001$). Within the scope of this study, 116

Table 1. The concepts and linked codes of ALSAQ-40 and ALSAQ-5

Item	Perspective	Response Classification	Main Concept	ICF Code
1			Walking short distances	d4602
2			Walking	d450
3			Walking	d450
4			Balance	b755
5			Focusing for walk	d160
6			Fatigue	b4552
7			Pain in legs	b28015
8			Climbing stairs	d4551
9			Stand up from any position	d4104*
10			Stand up while sitting	d4101
11			Arm and hand use for functionality	d445*
12			Turning and moving while lying in the bed	d4107
13			Pick something to up	d4400
14			Holding newspapers, books, turning pages	d440
15			Writing	d440
16			Doing houseworks	d170
17			Eating	d640
18			Caring hair and teeth	d520
19			Dressing	d5400
20			Washing hands	d5100
21	Appraisal	Frequency	Swallowing	b5105
22			Eating solid foods	d550*
23			Drinking liquids	d560
24			Conversation or communication with others	d350
25			Speaking	b330*
26			Speaking	d330
27			Speed of speaking	b3302
28			Speaking	d330
29			Speaking	d330
30			Conscious of speech	b152
31			Feeling lonely	b152
32			Feeling bored	b152
33			Feeling embarrassed	b152
34			Being hopeless	b152*
35			Being worried	b1522
36			Being anxious for health	b1301
37			Being angry	b1522
38			Feeling depressive	b1522
39			Being worried	b152
40			Feeling free	ND-MH

ICF: International Classification of Functioning, Disability and Health; ND-MH: Non-defined-Mental Health, *: Common items between ALSAQ-5 and ALSAQ-40.

items of four scales were examined, and 115 concepts were defined. Of the 115 concepts, 4 could not be linked to any ICF codes. These were defined as NC (2), ND-GH (1), and ND-MH (1), respectively. Of the linked concepts, 54 were body functions, 54 were activity and participation, and 4 were environmental factors. According to the perspective classification, 101 of the 116 items were determined as “appraisal” and 15 as “descriptive; capacity”. According to the response classification, 38 of the 116 items were determined as “intensity,” 57 as “frequency,” and 21 as “agreement.”

All concepts for the ALSAQ-5 were linked with ICF codes in Table 1. In the ALSAQ-40, 39 of the 40 concepts were linked with ICF in Table 1. In the ALSSQoL-R, 49 of the 50 concepts and all concepts for ALSSQoL-SF were linked with ICF codes in Table 2 and Table 3.

Discussion

Due to the progressive nature of ALS, both life expectancy and QoL of patients are adversely affected by the severity of the disease. The ICF allows many chronic and progressive diseases, such as ALS, to be examined in perspectives of a biopsychosocial model in accordance with patient expectations.

Moreover, the linking of current instruments with ICF helps in the selection of appropriate assessments and treatments, thereby improving the quality of clinical decision-making processes and healthcare services. From this perspective, the results of this study can be considered to contribute to the success of treatment and rehabilitation of patients with ALS and to the promotion of disease-specific core set development processes. The most important results of this study were that all but one item for the 4 concepts were linked with the ICF, and all the items of the ALSAQ-5 and ALSSQoL-SF, which are among the QoL outcomes developed and used specifically for individuals with ALS, were linked with ICF.

Previous studies have stated that ALSSQoL-R, ALSSQoL-SF, ALSAQ-40, and ALSAQ-5 have been used to evaluate the disease-specific QoL in individuals with ALS [20]. In addition to these instruments, the Sickness Impact Profile (SIP), and Short Form-36 (SF-36) have been used to assess health-related generic QoL, and the WHOQOL-Bref, McGill QoL Questionnaire (MQoLQ), Schedule for the Evaluation of Individual QoL (SEIQoL) has been used to assess global QoL of ALS patients [7]. Bernardelli et al. conducted a study based on refined rules of ICF linking for the SF-36 in 2021. A total of 67 concepts were

Table 2. The concepts and linked codes of ALSSQOL-R and ALSSQOL-SF.

R	S	Perspective	Response Classification	Main Concepts	Linked Codes
0		Appraisal	Intensity	General Quality of life	ND-GH
1	1			Pain	b2800
2	2			Fatigue	b4552
3				Eating	d550
4	3			Excessive Saliva	b5104
5		Descriptive; Capacity	Intensity	Mucous in throat	b510
6	4			Speaking	d330
7	5			Muscle strength for movement	b7
8	6			Sleep	b134
9				Urinary control; Defecation functions	b620; b525
10				Feeling dissatisfaction for physical health	b1522
11				Feeling positive emotions for life	b1265
12				Feeling positive emotions for coping with disease	b1265
13				Motivation for take control of own life	b130
14				Emotion of satisfaction	b130
15	8			Other people or things responding to person's needs	e3
16	9	Appraisal	Agreement	Feeling supported	e3
17				Not definable concept according to ICF	NC
18				Not definable concept according to ICF	NC
19				Satisfaction with own personality	b11420
20				Satisfaction with achieved goals	b1301
21				Optimistic thought about the future	b1265
22	10			Feeling depressed	b1522
23	12			Religion	d930
24				Communication with others	d3
25				Anxiety about the future	b1522
26	11	Appraisal	Intensity	Relationship with family and friends	d7101
27				Loss of interest to person and things	d7
28				Feeling sorrow	b152
29	13			Religion	d930*
30				Enjoyment of social interactions	d9205

R: ALSSQOL-R, S: ALSSQOL-SF, 0: Overall quality of life, ND-GH: Non-Defined General Health, NC: Not-Covered.

Table 3. The concepts and linked codes of 31 to 50 items of ALSSQOL-R.

R	S	Perspective	Response Classification	Main Concepts	Linked Codes
31				Feeling helpless	b152
32	14	Appraisal	Frequency	Feeling hopeless	b152
33	16			Feeling enjoyment with surroundings	b152
34	15			Feeling sad	b152
35				Religion	d930
36		Appraisal	Frequency	Feeling happy	b152
37				Feeling excitement	b147
38				Religion	d930
39		Appraisal	Agreement	Desire for social interactions	d710
40		Appraisal	Frequency	Relationship with family and friends	d9205
41		Appraisal	Intensity	Satisfaction of Relationship with family and friends	d7101
42	17	Appraisal	Aggrement	Emotional intimacy	d7
43	18	Appraisal	Frequency	Emotional intimacy with someone	d770
44		Appraisal	Intensity	Satisfaction of emotional intimacy	d7
45	19	Appraisal	Agreement	Physical intimacy	d7105
46	20	Appraisal	Frequency	Physical intimacy with someone	d7105
47		Appraisal	Intensity	Satisfaction of physical intimacy	d7105
48		Appraisal	Aggrement	Sexual Life	b640
49		Appraisal	Frequency	Sexual Life	b640
50		Appraisal	Intensity	Sexual Life	b640

R: ALSSQOL-R, S: ALSSQOL-SF.

identified, 49 of which could be linked to ICF. Approximately 22.4% of the concepts were linked to body functions, and 77.6% were linked to activity and participation components [21]. Prodinge et al., Geyh et al. and Cieza et al. similarly stated that SF-36 is mostly linked with the activity and participation component of the ICF [22-24]. In a systematic review conducted by Ballert et al., participation assessment tools were examined in terms of ICF linking. According to the results of the study, 63 concepts were determined to link SF-36 with ICF, and 22.2% of these concepts were linked to body functions, 52.4% to activity and participation, and 4.8% to environmental factors. In addition, 59.4% of the concepts for the SIP scale and 22.7% of the defined concepts for the WHOQoL-BREF scale were linked to activity and participation [25]. The results of the current study showed that the majority of the items of the ALSAQ-5, ALSAQ-40, ALSSQoL-SF, and ALSSQoL-R were linked with activity and participation parameters of ICF, which was consistent with the literature. To the best of our knowledge, there are no other studies in the literature that have examined the linking of disease-specific QoL instruments with ICF. From the findings of this study, it was concluded that the ALSAQ-5 assessed activity and participation parameters the most. However, the ALSAQ-40 had the most distinct association relative to the number of questions when considering the depth of coverage for the linked concepts. When diversity in perspective classification is required, ALSQoL-R has the most unique linking of any disease-specific QoL instrument for ALS. It was also observed that the items for the ALSQoL-SF were linked with activity and participation parameters at similar rates to those previously reported in the literature, and all of the concepts could be linked within the scope of ICF. The findings of the current study demonstrate that generic and global QoL instruments and ALS-specific QoL instruments are similar in

the context of rates for activity and participation. Bernardelli et al. showed that the linked concepts for SF-36 were distributed under the umbrella of general tasks and demands (d2), mobility (d4), self-care (d5), domestic life (d6), major life areas (d8), community, social and civic life (d9) and mental functions (b1) categories of ICF [21]. Similarly, according to Ballert et al., linked concepts for the SF-36 were distributed under the d4, d5, d8, and d9 categories. It has also been shown that concepts for SIP were linked with all d categories, and the linked concepts of WHOQoL-BREF were linked with d4, d7, d8, and d9 [25]. According to the results of the current study, the categories b1, and communication (d3), d4, d5 were linked with the short version of ALSAQ-40 (ALSAQ-5), and in addition to these categories, sensory functions and pain (b2), voice and speech functions (b3), functions of the cardiovascular, haematological, immunological and respiratory systems (b4), functions of the digestive, metabolic and endocrine systems (b5), neuromusculoskeletal and movement-related functions (b7), d1 and d6 categories were linked with ALSAQ-40. In addition, categories b1, b2, b4, b7, d3, d7, d9, and supports and relationships (e3) were linked with ALSSQoL-SF; categories b5, genitourinary and reproductive functions (b6), and d5 were linked to ALSSQoL-R. These differences from the literature can be attributed to the fact that the instruments examined in this study covered the specific symptoms of ALS. This emphasizes the importance of using disease-specific QoL scales. Another important piece of evidence from the current study is that all the instruments had items linked with items b152 “Emotional functions” and d330 “speaking” components. Therefore, clinicians and researchers who aim to evaluate these concepts in ALS patients should use all scales related to the study. In addition, fatigue, which is an important factor affecting disease progression, seems to be associated with all scales except the

ALSAQ-5.

When the differences between the instruments were examined, the ALSAQ-40 was found to be more inclusive in activities related to speech, voice, and mental functions; self-care; domestic life; and learning and applying knowledge. The ALSSQoL-R was found to be more inclusive in relation to ICF parameters in terms of mental, genitourinary, and reproductive functions, interpersonal communication, and social life. The ALSSQoL-R and ALSSQoL-SF can be considered to be useful tools for determining the functional capacity of patients since they contain a descriptive perspective. However, domains such as “products and technology, natural environment and human-made changes to environment, services, systems and policies, recreation, and leisure” that positively affect the QoL of patients with ALS and contribute to functionality and life span could not be associated with any of the instruments examined within the scope of this research. Therefore, it can be suggested that prioritizing these areas in the instruments to be developed in the future will contribute to the definition of QoL and inclusiveness of ICF. The results obtained from this study can be considered to contribute to target-oriented intervention approaches by providing guidance for the selection of an appropriate evaluation module.

Conclusion

For the first time in the literature, ALS-specific QoL instruments have been found to be mostly linked to ICF. The data obtained could contribute to the creation of a core set for ALS in the future and to the process of conducting clinical decision-making processes. The results of this research will also pave the way for the inclusion of the ICF perspective in the development of ALS-specific QoL instruments in the future.

Clinical Implications

- The ALSAQ-40 is identified as offering the most comprehensive coverage in terms of depth for linked concepts, making it a valuable tool for a broad assessment of ALS patients' needs.
- The ALSQoL-R is noted for its unique linking among disease-specific QoL instruments for ALS, providing a diverse perspective classification, essential for holistic patient assessment.
- Emotional functions and speaking components (b152 and d330 of ICF) are linked with all instruments, suggesting their essential role in evaluating ALS patients.
- The results provide crucial guidance for selecting appropriate evaluation modules, contributing to targeted intervention approaches in ALS patient care.

Limitations

The most important limitation of this study was the small number of instruments examined. There is a need for further research of instrument linking, specific to the symptoms of the disease (severity, cognitive and behavioral status, etc.), so that ALS can be more extensively studied from the perspective of ICF. It would also be of benefit to correlate linking studies conducted on different nationalities and cultures to be able to generalize the obtained data to all populations. Another significant limitation of our research is that the ICF does not differentiate between the domains of activity and participation. We believe that this presents a challenge in interpreting the effects of ALS on patient activities and their participation in various life areas. Further, we suggest the need for a more refined classification

system within the ICF or supplementary methods that can help delineate these two important components more clearly in future research.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and Human Rights Statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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